

HELPING PATRONS UNRAVEL THE MYSTERY OF GENETIC INFORMATION

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**Genetics
Overview**

**Genomic
Health
Literacy**

**Genetic
Testing**

**Consumer
Health
Resources**

**Ethics &
Privacy**

***All of Us*
Research
Program**

NNLM...?

NIH

- **National Institutes of Health**
- Nation's research agency

NLM

- **National Library of Medicine**
- World's largest biomedical library

NNLM

- **National Network of Libraries of Medicine**
- Program of the NLM comprised of 8 Regional Libraries (RMLs) and 6 offices

PNR

- **Pacific Northwest Region (NNLM PNR)**
- Is one of the 8 RMLs
- Serves Alaska, Idaho, Montana, Oregon, Washington



The mission of NNLM is to advance the progress of medicine and improve the public health by:

- Providing all U.S. health professionals with equal access to biomedical information
- Improving the public's access to information to enable them to make informed decisions about their health

Genetics in the News

Human Gene Editing Receives Science Panel's Support

Scientists Say They Hope To Create A
Human Genome In The Lab

Scientists Use Genetic Engineering To
Vanquish Disease-Carrying Insects

**Mail-Order CRISPR Kits Allow
Absolutely Anyone to Hack DNA**

**Baltimore Ravens to hand out
free DNA test kits**

**Clinical Genetics Has a Big
Problem That's Affecting
People's Lives**

Unreliable research can lead families to make health decisions they
might regret.

Genetically Modified Humans?
How Genome Editing Works

**Genetic
Testing for
Athletic Ability**

Can genes predict sporting talent?

Opioids: Can a Genetic Test
Identify an Addict in the
Making?

Signing up for 23andMe? You might be exposing your
family to the FBI

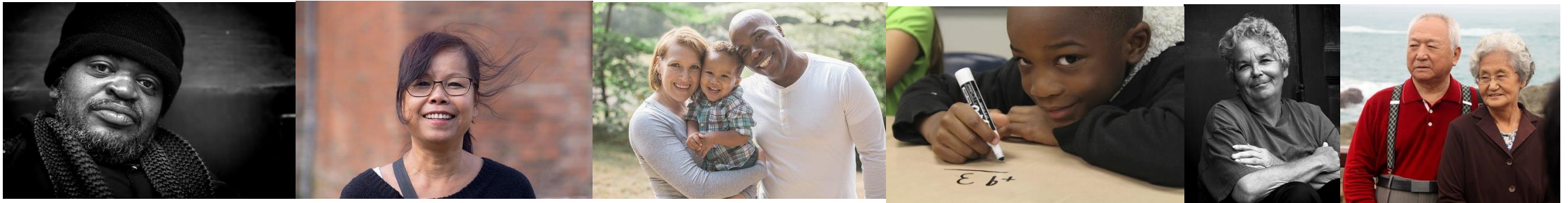
Birth of Baby With Three Parents' DNA Marks Success for Banned Technique

Genomic Health Literacy

Lack biology basics

Lack mathematical concepts

Low health literacy



Leading causes of death

1. Heart disease: 633,842
2. Cancer: 595,930
3. Chronic lower respiratory diseases: 155,041
4. Accidents (unintentional injuries): 146,571
5. Stroke (cerebrovascular diseases): 140,323
6. Alzheimer's disease: 110,561
7. Diabetes: 79,535
8. Influenza and pneumonia: 57,062
9. Nephritis, nephrotic syndrome, and nephrosis: 49,959
10. Intentional self-harm (suicide): 44,193

The Story of You



[The Story of You](#)








Genetic Testing

INCLUDING DIRECT-TO-CONSUMER

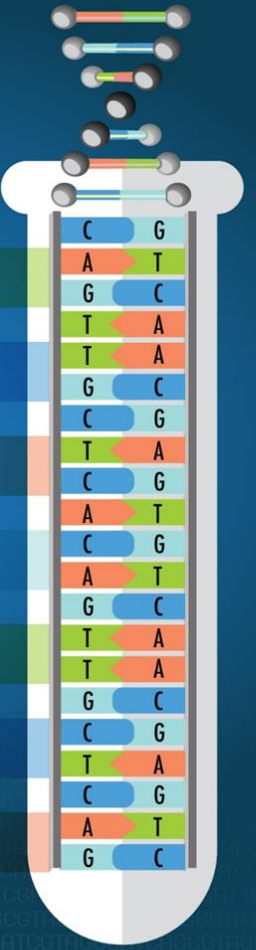
Clinical Uses of Genetic Tests

GENETIC TESTING
NHGRI FACT SHEETS
genome.gov

Genetic Tests Can Help to:

-  **Diagnose Your Disease**
-  **Pinpoint Genetic Factors That Caused Your Disease**
-  **Predict How Severe Your Disease Might Be**
-  **Choose the Best Medicine and Correct Dose**
-  **Discover Genetic Factors That Increase Your Disease Risk**
-  **Find Genetic Factors That Could Be Passed to Your Children**
-  **Screen Newborns for Certain Treatable Conditions**

Genetic Testing



Genetic Testing

Types of Genetic Tests

Diagnostic

Predictive

Carrier

Prenatal

Newborn
Screening

Research

Pharmacogenetic

Jean's Genetic Testing Timeline

Age 1 day: **newborn** testing for a few serious childhood diseases

Age 30: **carrier** testing (with her partner) before getting pregnant

Age 35: **predictive testing** when sister develops breast cancer at a young age

Age 45: **direct to consumer** genetic testing to investigate ancestry

Age 65: **pharmacogenomics** testing when Plavix wasn't effective



Genetic Testing Results

What genes and what variants did you test for?

- Different tests offered for the same conditions.
- Knowledge always changing.

Might not have enough examples in the database to determine associations between specific variants and specific conditions.

Might not have enough examples of people like you in the database.

Possibility of false positive and false negative results.

Genetic Testing- is it necessary?

Before testing:

- You think about your reasons for wanting the test
- You get the right test
- You and your family are prepared for the results
- You have a personalized plan for dealing with the results

Genetic Counselors

- Evaluate family history and medical records
- Assist in making decisions regarding genetic testing
- Identify and interpret risks of inherited disorders, increase the family's understanding of a genetic condition
- Discuss options regarding disease management and the risks and benefits of further testing and other options
- Help the individual and family identify the psychosocial tools required to cope with potential outcomes
- Reduce the family's anxiety

[National Society of Genetic Counselors](#)


Direct to Consumer Testing




Testing for talent




Achieve
your full potential.



Increase
your athletic performance.



Harness
your natural ability through
personalized genomics.



www.GenomicExpress.com

DNA dating



Pheramor



American College of Medical Genetics and Genomics

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ACMG STATEMENT | Genetics
in Medicine

Direct-to-consumer genetic testing: a revised position statement of the American College of Medical Genetics and Genomics

ACMG Board of Directors¹

Disclaimer: These recommendations are designed primarily as an educational resource for medical geneticists and other health-care providers to help them provide quality medical genetics services. Adherence to these recommendations does not necessarily assure a successful medical outcome. These recommendations should not be considered inclusive of all proper procedures and tests or exclusive of other procedures and tests that are reasonably directed to obtaining the same results. In determining the propriety of any specific procedure or test, geneticists and other

clinicians should apply their own professional judgment to the specific clinical circumstances presented by the individual patient or specimen. It may be prudent, however, to document in the patient's record the rationale for any significant deviation from the recommendations.

Genet Med advance online publication 17 December 2015

Key Words: consumer; direct-to-consumer; genetic testing; self-testing; OTC

With ongoing genetic discoveries and improvements in technology, more genetic tests are available than ever before. Along with greater availability has come increased consumer demand for genetic tests and expansion of direct-to-consumer testing. The American College of Medical Genetics and Genomics (ACMG) has revised its 2008 e-publication regarding this issue (ACMG Statement on Direct-to-Consumer Genetic Testing, retired; available by request to acmg@acmg.net) and believes that it is critical for the public to realize that genetic testing is only one part of a complex process that includes genetic risk

- A genetics expert such as a certified medical geneticist or genetic counselor should be available to help the consumer determine, for example, whether a genetic test should be performed and how to interpret test results in light of personal and family history. A board-certified genetic counselor can help facilitate this process by providing information about the test and helping to explain test results. A number of risks can be reduced if a board-certified genetics professional is involved in genetic testing, including inadequate or lack of informed consent.

ACMG

MedlinePlus

NIH U.S. National Library of Medicine

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Trusted Health Information for You

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[Health Topics](#) [Drugs & Supplements](#) [Videos & Tools](#)

Home → Health Topics → Genetic Testing

Genetic Testing

On this page

Basics <ul style="list-style-type: none"> Summary Start Here 	Learn More <ul style="list-style-type: none"> Related Issues Specifics 	See, Play and Learn <ul style="list-style-type: none"> No links available
Research <ul style="list-style-type: none"> Statistics and Research Clinical Trials Journal Articles 	Resources <ul style="list-style-type: none"> Reference Desk Find an Expert 	For You <ul style="list-style-type: none"> Patient Handouts

Summary

Genetic tests are tests on blood and other tissue to find **genetic disorders**. Over 2000 tests are available. Doctors use genetic tests for several reasons. These include

- Finding genetic diseases in unborn babies
- Finding out if people carry a gene for a disease and might pass it on to their children
- Screening embryos for disease
- Testing for genetic diseases in adults before they cause symptoms
- Making a diagnosis in a person who has disease symptoms
- Figuring out the type or dose of a medicine that is best for a certain person

People have many different reasons for being tested or not being tested. For some, it is important to know whether a disease can be prevented or treated if a test is positive. In some cases, there is no treatment. But test results might help a person make life decisions, such as family planning or insurance coverage. A **genetic counselor** can provide information about the pros and cons of testing.

NIH: National Human Genome Research Institute

Start Here

Get Genetic Testing updates
email

MEDICAL ENCYCLOPEDIA

- BRCA1 and BRCA2 gene tests
- Buccal smear
- Genetic testing and your cancer
- Karyotyping

Related Health Topics

FEDERAL TRADE COMMISSION

ESPAÑOL

Search

CONSUMER INFORMATION

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Direct-to-Consumer Genetic Tests

Could a simple medical test tell you if you are likely to get a particular disease? Could it evaluate your health risks and even suggest a specific treatment? Could you take this test in the privacy of your home, without a doctor's prescription or guidance?

Some companies say genetic testing can do all this and more. They claim that direct-to-consumer (DTC) genetic testing can screen for diseases and provide a basis for choosing a particular diet, dietary supplement, lifestyle change, or medication. These companies primarily sell their tests online and through multi-level marketing networks.

The Federal Trade Commission (FTC) wants you to know the facts about the DTC marketing of genetic tests.

Related Items

- [Anatomy of a Cancer Treatment Scam](#)
- [Dietary Supplements](#)
- [Miracle Health Claims](#)
- [Cancer Treatment Scams](#)

→ Genes and Genetic Tests
→ Interpreting the Results
→ Company Claims
→ If You're Considering a DTC Genetic Test
→ For More Information

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Healthy Living

Treatments & Cures

Weight Loss & Fitness

JOBS & MAKING MONEY

PRIVACY, IDENTITY & ONLINE SECURITY

BLOG

VIDEO & MEDIA

Genetics Home Reference



Your Guide to Understanding
Genetic Conditions

Search



Health Conditions

Genes

Chromosomes & mtDNA

Resources

Help Me Understand Genetics

What is direct-to-consumer genetic testing?

Most of the time, genetic testing is done through healthcare providers such as physicians, nurse practitioners, and genetic counselors. Healthcare providers determine which test is needed, order the test from a laboratory, collect and send the DNA sample, interpret the test results, and share the results with the patient. Often, a health insurance company covers part or all of the cost of testing.

Direct-to-consumer genetic testing is different: these genetic tests are marketed directly to customers via television, print advertisements, or the Internet, and the tests can be bought online or in stores. Customers send the company a DNA sample and receive their results directly from a secure website or in a written report. Direct-to-consumer genetic testing provides people access to their genetic information without necessarily involving a healthcare provider or health insurance company in the process.

Dozens of companies currently offer direct-to-consumer genetic tests for a variety of purposes. The most popular tests use genetic variations to make predictions about health, provide information about common traits, and offer clues about a person's ancestry. The number of companies providing direct-to-consumer genetic testing is growing, along with the range of health conditions and traits covered by these tests. Because there is currently little regulation of direct-to-consumer genetic testing services, it is important to assess the quality of available services before pursuing any testing.

Other names for direct-to-consumer genetic testing include DTC genetic testing, direct-access genetic testing, at-home genetic testing, and home DNA testing. [Ancestry testing](#) (also called genealogy testing) is also considered a form of direct-to-consumer genetic testing.

For more information about to-consumer genetic testing

Centers for Disease Control and Prevention (CDC) Genomics and Impact Blog: [Direct to Consumer Genetic Testing: Think Before You Spit, 2nd Edition!](#)

National Society of Genetic Counselors: [What is At-Home Genetic Testing?](#)

American Medical Association: [Direct-to-Consumer Genetic Testing](#)

The Federal Trade Commission: [Consumer Genetic Tests](#)

Genes in Life: [Direct-to-Consumer Genetic Testing](#)

Johns Hopkins Medicine: [Five Things to Know about Direct-to-Consumer Genetic Tests](#)

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[Consumer Genetic Tests](#)

Genes in Life: [Direct-to-Consumer Genetic Testing](#)

Johns Hopkins Medicine: [Five Things to Know about Direct-to-Consumer Genetic Tests](#)

Printable Chapter PDF (1MB)

Topics in the Direct-to-Consumer Genetic Testing chapter

What is direct-to-consumer genetic testing?

[What kinds of direct-to-consumer genetic tests are available?](#)

[What is genetic ancestry testing?](#)

[What are the benefits and risks of direct-to-consumer genetic testing?](#)

[How do I choose a direct-to-consumer genetic testing company?](#)

[How is direct-to-consumer genetic testing done?](#)

[How much does direct-to-consumer genetic testing cost, and is it covered by health insurance?](#)

[What do the results of direct-to-consumer genetic testing mean?](#)

[What can raw data from a direct-to-consumer genetic test tell me?](#)

[Can a direct-to-consumer genetic test tell me whether I will develop cancer?](#)

[Can a direct-to-consumer genetic test tell me whether I will develop Alzheimer disease?](#)

[What does it mean to have Neanderthal or Denisovan DNA?](#)

[How do direct-to-consumer genetic testing companies protect their customers' privacy?](#)

[Can the results of direct-to-consumer genetic testing affect my ability to get insurance?](#)

Concerns

- Privacy and legality
- Who has access?
- What all is being done now and in the future with the information?
- Unexpected surprises?
- Test results can vary among companies
- Validity of tests
- No counseling provided

Benefits

- Learn more about own health
- Learn more about ethnicity and family history
- Bring awareness to family health issues for future generations
- Motivation to work on health habits
- Encourages patient engagement
- Contributing to advancement of healthcare and science
- Moral obligation

Questions to ask before using a Direct to Consumer Genetic Test

- Is the test right for me?
- What are the company claims?
- What do I hope to find out?
- Am I ready to hear something unexpected?
- Who will the results affect besides me?
- What happens to my genetic information?



Think After You Spit

- Have a healthy dose of skepticism
- Discuss and share the results of tests with health care providers
- Seek, collect and validate as much as possible family health history
- There are general disease prevention and health promotion messages that are important (stop smoking, exercise, etc.)
- Learn about health and disease and become involved in both family and patient-provider interactions

[Think After You Spit- CDC](#)

Consumer Resources

PATIENT AND K-12 EDUCATION

MedlinePlus



MedlinePlus

- Section: Genetics/Birth Defects
- Health Topic pages:
 - Genetics
 - Genetic testing
 - Genetic counseling
 - Genetic disorders
 - Genetic brain disorders
 - Genes and gene therapy
- text word search

MedlinePlus – Genetics topics

[Health Topics](#) [Drugs & Supplements](#) [Videos & Tools](#)

Home → [Health Topics](#) → [Genetics/Birth Defects](#)

Genetics/Birth Defects

[Abnormalities](#) [see Birth Defects](#)

[Achondroplasia](#) [see Dwarfism](#)

[Adrenoleukodystrophy](#) [see Leukodystrophies](#)

[Alpha-1 Antitrypsin Deficiency](#)

[Amniocentesis](#) [see Prenatal Testing](#)

[Anencephaly](#) [see Neural Tube Defects](#)

[Arnold-Chiari Malformation](#) [see Chiari Malformation](#)

[Ataxia](#) [see Friedreich's Ataxia](#)

[Ataxia Telangiectasia](#)

[Birth Defects](#)

[Blood Coagulation Disorders](#) [see Hemophilia](#)

[Brain Disorders, Inborn Genetic](#) [see Genetic Brain Disorders](#)

[Brain Malformations](#)

[Canavan Disease](#) [see Leukodystrophies](#)

[Cephalic Disorders](#) [see Brain Malformations](#)

[Cerebral Palsy](#)

[Charcot-Marie-Tooth Disease](#)

[Chiari Malformation](#)

[Chorionic Villi Sampling](#) [see Prenatal Testing](#)

[Cleft Lip and Palate](#)

[Cleft Palate](#) [see Cleft Lip and Palate](#)

[Cleft Spine](#) [see Spina Bifida](#)

[Cloning](#)

[Color Blindness](#)

[Congenital Heart Defects](#)

MedlinePlus – stroke topic page

NIH U.S. National Library of Medicine

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Health Topics Drugs & Supplements Videos & Tools **Español**

Home → Health Topics → Stroke

Stroke

Also called: Brain attack, CVA

On this page

Basics	Learn More	See, Play and Learn
<ul style="list-style-type: none"> Summary Start Here Symptoms Diagnosis and Tests Prevention and Risk Factors Treatments and Therapies 	<ul style="list-style-type: none"> Related Issues Genetics 	<ul style="list-style-type: none"> Images Health Check Tools Videos and Tutorials

Research Resources For You

Research	Resources	For You
<ul style="list-style-type: none"> Statistics and Research Clinical Trials Journal Articles 	<ul style="list-style-type: none"> Reference Desk Find an Expert 	<ul style="list-style-type: none"> Children Women Seniors Patient Handouts

Summary

A stroke is a medical emergency. Strokes happen when blood flow to your brain stops. Within minutes, brain cells begin to die. There are two kinds of stroke. The more common kind, called **ischemic stroke**, is caused by a **blood clot** that blocks or plugs a blood vessel in the brain. The other kind, called **hemorrhagic stroke**, is caused by a blood vessel that breaks and bleeds into the brain. "Mini-strokes" or **transient ischemic attacks (TIAs)**, occur when the blood supply to the brain is briefly interrupted.

Symptoms of stroke are

- Sudden numbness or weakness of the face, arm or leg (especially on one side of the body)
- Sudden confusion, trouble speaking or understanding speech
- Sudden trouble seeing in one or both eyes
- Sudden trouble walking, dizziness, loss of balance or coordination
- Sudden severe headache with no known cause

Get Stroke updates by email

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MEDICAL ENCYCLOPEDIA

BAER - brainstem auditory evoked response

Brain herniation

Brain surgery

Brain surgery - discharge

Craniotomy - slideshow

EEG

Specifics

- Hemorrhagic Stroke: MedlinePlus Health Topic** (NIH) (National Library of Medicine)
Also in Spanish
- Ischemic Stroke: MedlinePlus Health Topic** (NIH) (National Library of Medicine)
Also in Spanish
- Spinal Cord Infarction** (NIH) (National Institute of Neurological Disorders and Stroke)
- Wallenberg's Syndrome** (NIH) (National Institute of Neurological Disorders and Stroke)

Genetics

- Genetics Home Reference: cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy** (NIH) (National Library of Medicine)
- Genetics Home Reference: Grange syndrome** (NIH) (National Library of Medicine)
- Genetics Home Reference: mitochondrial encephalomyopathy, lactic acidosis, and stroke-like episodes** (NIH) (National Library of Medicine)
- Genetics Home Reference: moyamoya disease** (NIH) (National Library of Medicine)

Images

- Craniotomy - slideshow** (Medical Encyclopedia)
Also in Spanish

Health Check Tools

- Test Your Stroke Knowledge** (NIH) (National Institute of Neurological Disorders and Stroke)
- What's Your Stroke I.Q.?** (American Heart Association)

Videos and Tutorials

- Know Stroke: Know the Signs, Act in Time Video** (NIH) (National Institute of Neurological Disorders and Stroke)

Statistics and Research

- FastStats: Cerebrovascular Disease or Stroke** (National Center for Health Statistics)
- Heart Disease and Stroke Statistics** (American Heart Association)
- Preventing Stroke Deaths** (Centers for Disease Control and Prevention)
Also in Spanish

Clinical Trials

- ClinicalTrials.gov: Carotid Stenosis** (NIH) (National Institutes of Health)
- ClinicalTrials.gov: Cerebrovascular Disorders** (NIH) (National Institutes of Health)

MedlinePlus – text search

The screenshot shows the MedlinePlus website interface. At the top, the NIH logo and 'U.S. National Library of Medicine' are visible. Below this is the MedlinePlus logo with the tagline 'Trusted Health Information for You'. A search bar at the top right contains the word 'genetics' and a 'GO' button. Below the search bar are links for 'About MedlinePlus', 'Site Map', 'FAQs', 'Custom', and 'Support'. A navigation bar below the search bar includes 'Health Topics', 'Drugs & Supplements', 'Videos & Tools', and a language selector for 'Español'. The main content area shows 'Home → Search Results' and a 'Search Help' link. On the left, there are sections for 'Related Topics' (Seizures, Epilepsy, Ovarian Cancer, Breast Cancer, Genetic Counseling) and 'Refine by Type' (All Results: 8,846; Health Topics: 390; External Health Links: 4,757; Drugs and Supplements: 36; Medical Encyclopedia: 418; MedlinePlus Magazine: 205; Multiple Languages; National Institutes of Health: 2,832). Below this is 'Refine by Format' (All Results: 8,846; PDF: 153; Images: 36; Videos: 19). The main content area features a 'Genetic Disorders' section with a blue header, a paragraph about genes, a small image of chromosomes, and a paragraph about mutations. Below this is a 'Results 1 - 10 of 5,973 for genetics' section with three results: 1. Genetic Disorders (National Library of Medicine), 2. Genetic Brain Disorders (National Library of Medicine), and 3. Genetic Counseling (National Library of Medicine). Each result includes a brief description and a link to the full article.

Text word search 'genetics'

Genetics Home Reference

The screenshot shows the homepage of the Genetics Home Reference website. At the top is a blue header with the NIH logo and the text 'U.S. NATIONAL LIBRARY OF MEDICINE'. Below this is a navigation bar with the 'Genetics Home Reference' logo, the tagline 'Your Guide to Understanding Genetic Conditions', and a search bar. A secondary navigation bar contains links for 'Health Conditions', 'Genes', 'Chromosomes & mtDNA', 'Resources', and 'Help Me Understand Genetics'. The main content area features a large banner with the text 'Genetics Home Reference provides consumer-friendly information about the effects of genetic variation on human health.' Below the banner, there are three main sections: 'Health Conditions' with a description 'More than 1,100 health conditions, diseases, and syndromes' and a 'Browse A-Z' button; a 'New & Updated' section with a list of recent updates including 'Hartnup disease', 'multiple myeloma', and 'SYNGAP1-related intellectual disability'; and a 'Genes' section at the bottom left with a DNA helix icon.

- Health conditions
- Genes
- Chromosomes and DNA
- Resources
- Genetic handbook (Help Me Understand Genetics)

[Genetics Home Reference](#)

Genetics Home Reference- health conditions



Your Guide to Understanding
Genetic Conditions

Search



Health Conditions

Genes

Chromosomes & mtDNA

Resources

Help Me Understand Genetics



Health Conditions

Explore the signs and symptoms, genetic cause, and inheritance pattern of various health conditions.

0 - 9 A B C D E F G H I J K L M N O P
Q R S T U V W X Y Z

A-alpha1ipoprotein Neuropathy, see [Tangier disease](#)

A-T, see [Ataxia-telangiectasia](#)

AAA, see [Triple A syndrome](#)

AAA syndrome, see [Triple A syndrome](#)

AADC deficiency, see [Aromatic L-amino acid decarboxylase deficiency](#)

Aarskog syndrome, see [Aarskog-Scott syndrome](#)

[Aarskog-Scott syndrome](#)

AAS, see [Aarskog-Scott syndrome](#)

AASA dehydrogenase deficiency, see [Pyridoxine-dependent epilepsy](#)

Aase syndrome, see [Diamond-Blackfan anemia](#)

Aase-Smith syndrome II, see [Diamond-Blackfan anemia](#)

AAT, see [Alpha-1 antitrypsin deficiency](#)

AATD, see [Alpha-1 antitrypsin deficiency](#)

AB variant, see [GM2-gangliosidosis, AB variant](#)

ABCB11-related intrahepatic cholestasis, see [Progressive familial intrahepatic cholestasis](#)

Learn More about Health Conditions

What does it mean if a disorder seems to run in my family?

What are the different ways in which a genetic condition can be inherited?

What are complex or multifactorial disorders?

What does it mean to have a genetic predisposition to a disease?

Genetics Home Reference



Your Guide to Understanding
Genetic Conditions

Health Conditions Genes Chromosomes & mtDNA Resources Help Me Understand Genetics

Williams syndrome

Printable PDF Open All Close All

Description

Williams syndrome is a developmental disorder that affects many parts of the body. This condition is characterized by mild to moderate intellectual disability or learning problems, unique personality characteristics, distinctive facial features, and heart and blood vessel (cardiovascular) problems.

People with Williams syndrome typically have difficulty with visual-spatial tasks such as drawing and assembling puzzles, but they tend to do well on tasks that involve spoken language, music, and learning by repetition (rote memorization). Affected individuals have outgoing, engaging personalities and tend to take an extreme interest in other people. Attention deficit disorder (ADD), problems with anxiety, and phobias are common among people with this disorder.

Young children with Williams syndrome have distinctive facial features including a [broad forehead](#), a [short nose](#) with a broad tip, [full cheeks](#), and a [wide mouth](#) with full lips. Many affected people have dental problems such as teeth that are small, widely spaced, crooked, or missing. In older children and adults, the face appears longer and more gaunt.

A form of cardiovascular disease called [supravalvular aortic stenosis](#) (SVAS) occurs frequently in people with Williams syndrome. Supravalvular aortic stenosis is a narrowing of the large blood vessel that carries blood from the heart to the rest of the body ([the aorta](#)). If this condition is not treated, the aortic narrowing can lead to shortness of breath, chest pain, and heart failure. Other problems with the heart and blood vessels, including high blood pressure (hypertension), have also been reported in people with Williams syndrome.

Additional signs and symptoms of Williams syndrome include abnormalities of connective tissue (tissue that supports the body's joints and organs) such as joint problems and soft, loose skin. Affected people may also have increased calcium levels in the blood (hypercalcemia) in infancy, developmental delays, problems with coordination, and short stature. Medical problems involving the eyes and vision, the digestive tract, and the [urinary system](#) are also possible.

Related Information

[What does it mean if a disorder seems to run in my family?](#)

[What is the prognosis of a genetic condition?](#)

[Genetic and Rare Diseases Information Center](#)



Your Guide to Understanding
Genetic Conditions

Health Conditions Genes Chromosomes & mtDNA Resources Help Me Understand Genetics

Williams syndrome

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Description

Frequency

Genetic Changes

Inheritance Pattern

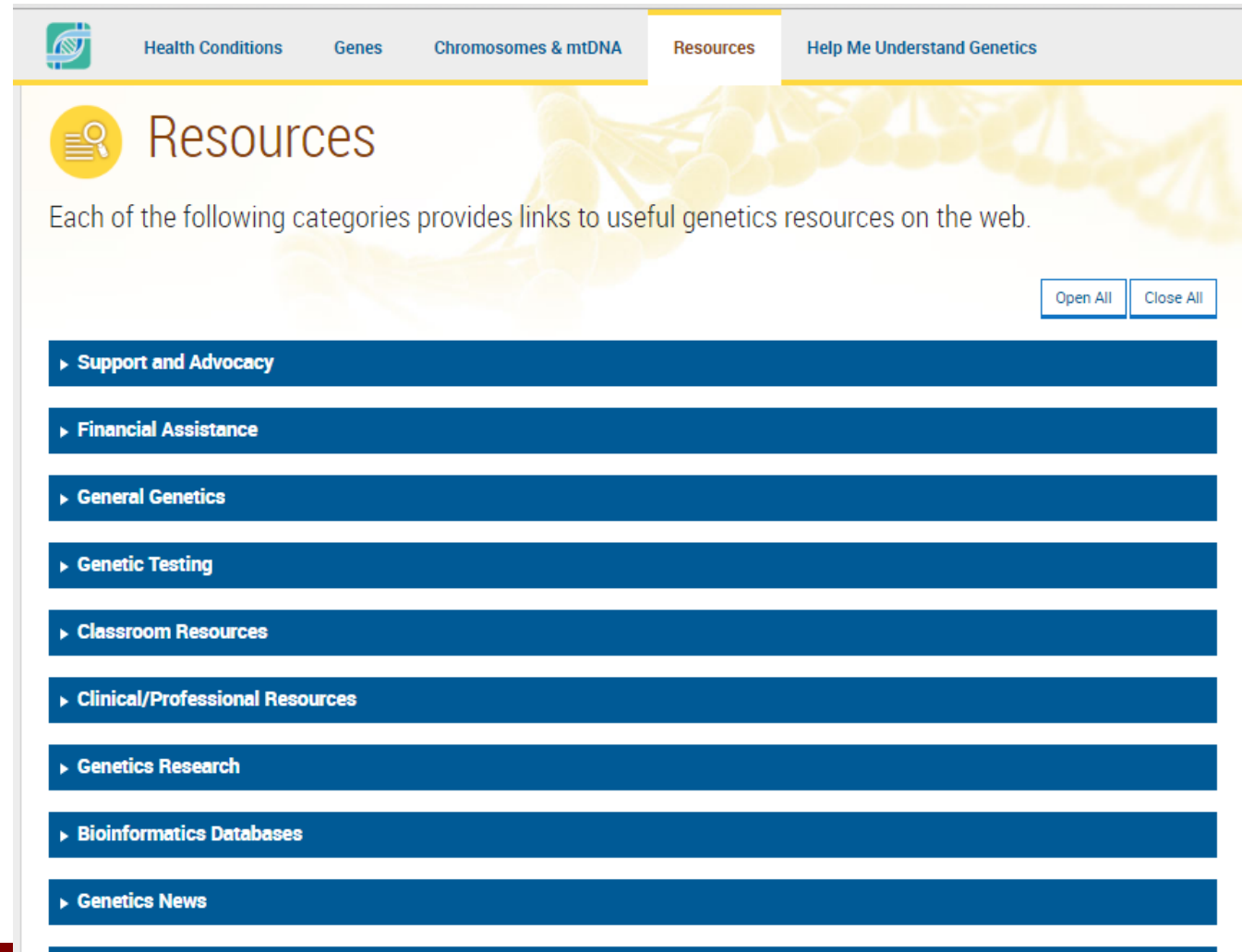
Diagnosis & Management Resources

Other Names for This Condition

Additional Information & Resources

Sources for This Page

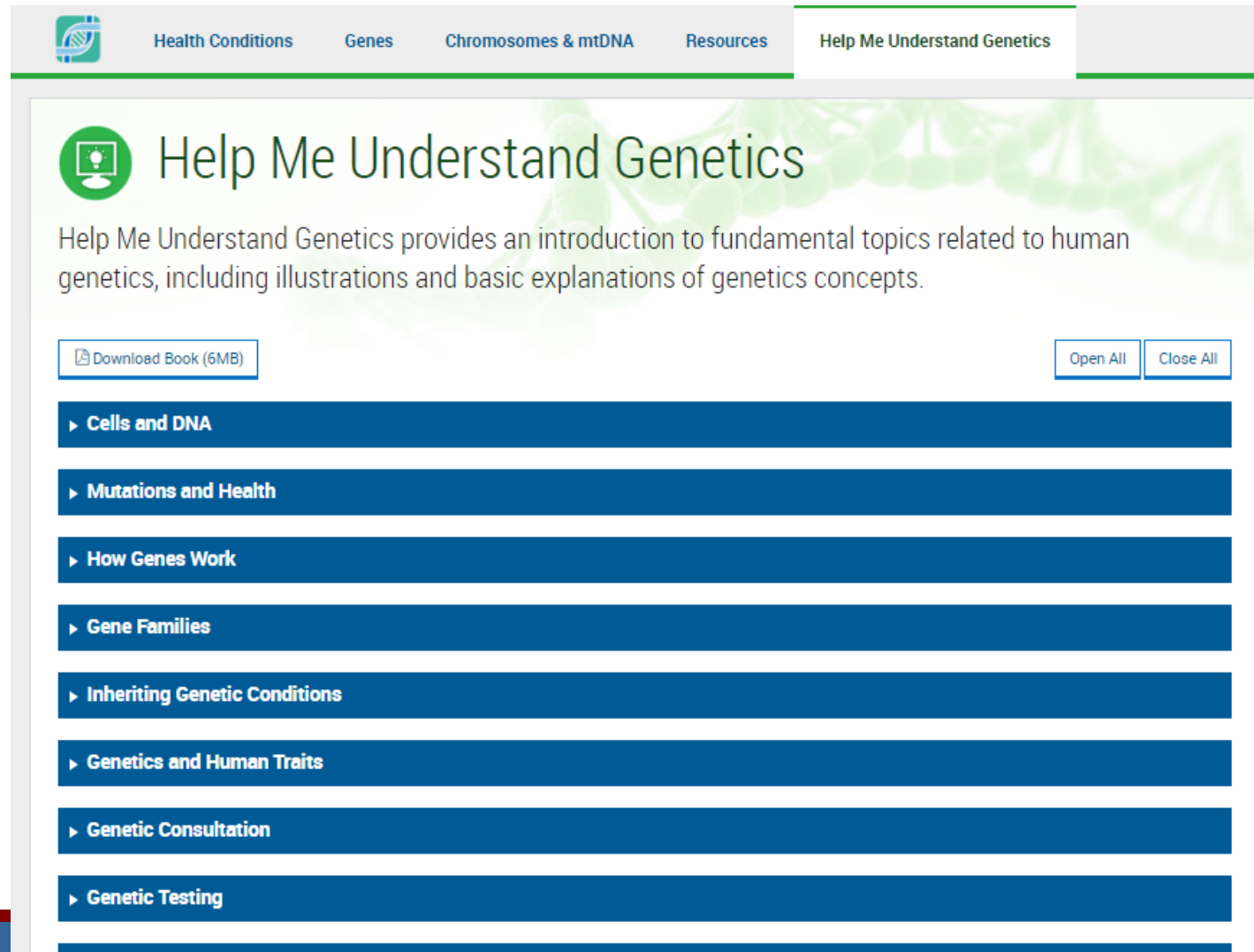
Genetics Home Reference- resources



The screenshot shows the 'Resources' section of the Genetics Home Reference website. The navigation bar at the top includes links for 'Health Conditions', 'Genes', 'Chromosomes & mtDNA', 'Resources' (which is highlighted), and 'Help Me Understand Genetics'. The main heading 'Resources' is accompanied by a magnifying glass icon. Below the heading, a text block states: 'Each of the following categories provides links to useful genetics resources on the web.' To the right of this text are two buttons: 'Open All' and 'Close All'. A list of ten resource categories is displayed as blue bars with white text and a right-pointing arrow:

- ▶ Support and Advocacy
- ▶ Financial Assistance
- ▶ General Genetics
- ▶ Genetic Testing
- ▶ Classroom Resources
- ▶ Clinical/Professional Resources
- ▶ Genetics Research
- ▶ Bioinformatics Databases
- ▶ Genetics News

Genetics Home Reference- handbook



The screenshot shows the 'Help Me Understand Genetics' page from the National Library of Medicine. The page has a navigation bar with links to 'Health Conditions', 'Genes', 'Chromosomes & mtDNA', 'Resources', and 'Help Me Understand Genetics'. The main content area features a green circular icon with a lightbulb and the title 'Help Me Understand Genetics'. Below the title, a paragraph states: 'Help Me Understand Genetics provides an introduction to fundamental topics related to human genetics, including illustrations and basic explanations of genetics concepts.' There are two buttons: 'Download Book (6MB)' and 'Open All'. A list of topics is displayed as blue bars with white text, each preceded by a right-pointing triangle icon. The topics are: 'Cells and DNA', 'Mutations and Health', 'How Genes Work', 'Gene Families', 'Inheriting Genetic Conditions', 'Genetics and Human Traits', 'Genetic Consultation', and 'Genetic Testing'.

Health Conditions Genes Chromosomes & mtDNA Resources Help Me Understand Genetics


Help Me Understand Genetics

Help Me Understand Genetics provides an introduction to fundamental topics related to human genetics, including illustrations and basic explanations of genetics concepts.

[Download Book \(6MB\)](#) [Open All](#) [Close All](#)

- ▶ Cells and DNA
- ▶ Mutations and Health
- ▶ How Genes Work
- ▶ Gene Families
- ▶ Inheriting Genetic Conditions
- ▶ Genetics and Human Traits
- ▶ Genetic Consultation
- ▶ Genetic Testing

NIH National Human Genome Research Institute- health information



National Human Genome Research Institute

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Español


Research Funding
Research at NHGRI
Health
Education
Issues
Newsroom
Careers
About

Highlights




The 2018 Jeffrey M. Trent Lecture in Cancer Research

NHGRI's Division of Intramural Research will present the 14th Jeffrey M. Trent Lecture in Cancer Research on March 15, 2018, 12:00 - 1:00 p.m., at the Lipsett Amphitheater, Building 10 (Clinical Center), on the National Institutes of Health Bethesda campus. Joan Brugge, Ph.D., co-director, Ludwig Center at Harvard Medical School, will deliver the lecture *Role of the TRPA1 Ca2+-permeable Channel in Oxidative Stress Defenses in Cancer*. Watch it at Genome TV Live on March 15 starting at 12:00 p.m. Eastern.



NIH researchers highlight virtual reality research on Reddit

Virtual Reality (VR) is a rapidly expanding area in tech and gaming. Now it's also playing an important role in medicine and health, expanding opportunities for researchers, clinicians and patients. Simulated experience can reduce stress, help doctors practice surgical techniques or allow medical students a way to practice their bedside manner in virtual scenarios. On February 23, NHGRI hosted a Reddit "Ask Me Anything" (AMA) with NIH researchers who use VR to study a host of research questions. Read our recap here.



NIH pilot project will match researchers to genes, gene variants of interest

The National Institutes of Health and Inova have launched a new match-making service between genes and gene variants and the researchers who study them. The Genomic Ascertainment Cohort (TGAC) project will be based in the Washington, D.C., area so that researchers can recall genotyped participants to examine the genes and gene variants that influence their phenotype.

Email Updates

Enter your email
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Genomics News


From the African Academy of Sciences: **African Academy of Sciences awards grants to better understand the diseases that affect Africa most**
March 1, 2018


From The National Institute of Environmental and Health Sciences: **Building Capacity in Africa for Genomics and Environmental Health Research**
February 20, 2018


From The Ohio State University Comprehensive Cancer Center: **New Report Labs Differ Widely in BRCA Testing Protocols**
February 16, 2018


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Quick Links


Director Eric Green


Strategic Planning






National Human Genome Research Institute

Search Genome.gov

Español

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Research at NHGRI
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Issues
Newsroom
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About

Health

Information about genetics and genomics, rare diseases, patient care and more

For Patients and the Public

Detailed information about genetic disorders, background on genetic and genomic science, pharmacogenomics, family health history tool and online health resources

- Community Engagement and Community Health
- Family History
- Genetics & Genomics Science & Research
- Genetic & Rare Diseases Information Center
- Genomic Medicine and Health Care
- Online Health and Support Resources
- Specific Genetic Disorders

For Health Professionals

Genetics and genomics information related to patient management, education, NIH and NHGRI research and ethical, legal and social issues

- Competency & Curricular Resources
- Genetics 101
- Genomic Medicine and Health Care
- Inter-Society Coordinating Committee (ISCC)
- New Horizons and Research
- Patient Management
- Policy and Ethics Issues

Highlights

Researchers pinpoint origin of sickle cell mutation

NHGRI researchers used whole genome sequence data to pinpoint the single origin of the sickle cell mutation to the "wet" period of the Sahara 7,300 years ago. The mutation causes blood hemoglobin to be crescent shaped, reducing its ability to carry oxygen. Charles N. Rotimi, Ph.D., study co-author and NHGRI senior investigator, said the finding overturns previous theories that the mutation arose in multiple locations. This will help clinicians redefine sickle cell subgroups and treat patients more effectively, said lead author Daniel Shriner, Ph.D. Read more in the March 8 *American Journal of Human Genetics*.

See Also

- GenomeTV
- Genomic Healthcare Branch
- Fact Sheets
- Genetic Education Resources for Teachers
- All About the Human Genome Project
- Health Archive
- On Other Sites:
- NHGRI's YouTube channel: GenomeTV

Reddit "Ask Me Anything" Recap: The importance of knowing your family health history

NHGRI

National Organization for Rare Disorders

The screenshot shows the NORD website homepage. At the top, there is a navigation bar with links for ABOUT, NEWS, EVENTS, CONTACT, and a prominent orange DONATE button. The NORD logo and a 35th Anniversary banner are on the left, while a search bar and social media icons are on the right. Below the navigation bar, a horizontal menu lists various audience groups: PATIENTS AND FAMILIES, PATIENT ORGANIZATIONS, INDUSTRY, CLINICIANS AND RESEARCHERS, ADVOCATE, and GET INVOLVED. The main banner features a collage of diverse people's faces with the text: "7,000 RARE DISEASES AFFECT 30 MILLION AMERICANS. HOW CAN YOU HELP? #DOYOURSHARE" and the website "DoYourShare.com". Below the banner, a section titled "What's happening at NORD" contains four promotional tiles: "RARE DISEASE DAY" with a colorful hand logo, "RARE IMPACT AWARDS" for May 17, 2018 in Washington, D.C. with "Registration Open!", "Rare Summit" featuring the U.S. Capitol dome, and "RUNNING FOR RARE" with "Accepting Applications". At the bottom, there are links for "Tools and Resources" and "News".

ABOUT NEWS EVENTS CONTACT **DONATE**

NORD
National Organization for Rare Disorders

35th ANNIVERSARY

Search     

for PATIENTS AND FAMILIES | for PATIENT ORGANIZATIONS | for INDUSTRY | for CLINICIANS AND RESEARCHERS | ADVOCATE | GET INVOLVED

**7,000 RARE DISEASES
AFFECT 30 MILLION AMERICANS.
HOW CAN YOU HELP? #DOYOURSHARE**

DoYourShare.com

What's happening at NORD


RARE DISEASE DAY®



presenting the
RARE IMPACT AWARDS™
May 17, 2018 • Washington, D.C.
Registration Open!


Rare Summit


Accepting Applications

Tools and Resources News

Education Resources


National Human Genome Research Institute


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Education


Educational materials about genetics and genomics



Smithsonian NHGRI Genome Exhibition
A genomics exhibition from the Smithsonian and NHGRI



About The Human Genome Project
Information on the history, progress and impact of the HGP



Talking Glossary of Genetic Terms
Terms and definitions used in genetic research with multimedia



Genomic Careers
Information on careers in genomics and genetics


National DNA Day
A unique day when everyone can learn more about genomics and genetics


Genetic Education Resources for Teachers
Teaching plans to present the science of genetics and genomics



Online Genetic Education Resources
A list of online resources for learning about genomics and genetics


Fact Sheets
Clearly written information on the institute, genetic research and genetic concepts



Online Education Kit
A web-based resource outlining the major history and developments of genomics

Highlights


The 2018 National DNA Day Essay Contest is open!


Geared to students grade 9-12 worldwide, the American Society of Human Genetics (ASHG) DNA Day Essay Contest celebrates National DNA Day by asking students to examine, question and reflect on important concepts in genetics. This year's question asks students if medical professionals should be required for all genetic testing, or should consumers have direct access to predictive genetic testing? **Deadline:** March 9, 2018, at 5:00 p.m. U.S. Eastern Time.

Genome Unlocking Life's Code goes international!


Genome: Unlocking Life's Code, the traveling genomics science exhibit created by NHGRI and the Smithsonian National Museum of Natural History, needs a passport ... because it's going international for the first time! The exhibit will move on to Science North in Sudbury,

See Also
[Education and Community Involvement Branch](#)
[GenomeTV](#)
[Genome Advance of the Month](#)
[Education Archive](#)
On Other Sites:
[Genome: Unlocking Life's Code](#)
[NHGRI Smithsonian Exhibition](#)
[GenomeTV](#)
[NHGRI's YouTube Channel](#)


[Health Conditions](#)
[Genes](#)
[Chromosomes & mtDNA](#)
[Resources](#)
[Help Me Understand Genetics](#)

Help Me Understand Genetics

Help Me Understand Genetics provides an introduction to fundamental topics related to human genetics, including illustrations and basic explanations of genetics concepts.

[Download Book \(6MB\)](#)
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[Close All](#)

- ▶ Cells and DNA
- ▶ Mutations and Health
- ▶ How Genes Work
- ▶ Gene Families
- ▶ Inheriting Genetic Conditions
- ▶ Genetics and Human Traits
- ▶ Genetic Consultation
- ▶ Genetic Testing

National DNA Day- April 25

National DNA DAY APRIL 25
15th Anniversary

Celebrating Genomics Through Awareness

[About DNA Day](#)
[Find Events](#)
[Celebrate With NHGRI](#)
[Get Activity Ideas](#)
[Get Starter Kit](#)
[Register An Event](#)

National DNA Day

15 for 15 Celebration

- April 05: DNA Sequencing
- April 06: Human Genomic Variation
- April 09: Cancer Genomics
- April 10: Human Origins and Ancestry

[About DNA Day](#)
[Celebrate with NHGRI](#)
[Find Events](#)
[Get Activity Ideas](#)
[Get Starter Kit](#)
[Register an Event](#)

Learn about the Celebration

15 for 15

'15 for 15' Celebration

Fifteen ways genomics is now influencing our world



Whether you realize it or not, many parts of our daily lives are influenced by genomic information. Genomics now provides a powerful lens for use in various areas - from medical decisions, to food safety, to environmental protection.

April 2018 will mark the 15th anniversary of the completion of the Human Genome Project. In celebration of genomic advances that have been made since 2003, the National Human Genome Research Institute (NHGRI) is launching the '15 for 15' Celebration - unveiling 15 ways that genomics has and will continue to transform our world.

We hope that you will join us on this journey and learn how genomics is influencing the world you discover today?



Celebrate with NHGRI

- Bench to Bedside to Business
- Smithsonian Hot Topic - Lita Proctor, Ph.D.

The National DNA Day Reddit "Ask Me Anything" Series

April 20 and April 23-27, 2018

National DNA DAY APRIL 25
15th Anniversary

"Ask Me Anything" (AMA) Series

On the reddit science community forum **"r/Science"**
Featuring prominent geneticists from a range of research areas

April 20 & April 23-27, 2018

The National Human Genome Research Institute (NHGRI) will launch the National DNA Day Reddit "Ask Me Anything" (AMA) Series on Friday, April 20, continuing each week day until Friday, April 27, 2018, from 1:00 - 3:00 p.m. Eastern. Genomics experts will answer questions at the Reddit Science community forum, **"r/Science"**. A Reddit AMA is an opportunity to ask interesting individuals questions about anything and everything.

Series Events

Friday, April 20, 2018

National Institutes of Health Director Francis Collins, M.D., Ph.D.

"The future of precision medicine"

The former director of the NHGRI, Dr. Collins earned a reputation as a gene hunter at the **University of Michigan** and subsequently lead the successful completion of the Human Genome Project 15 years ago. Now, in his current role as the director of the National Institutes of Health (NIH), Dr. Collins manages the NIH's efforts in building innovative enterprises, such as the **All of Us Research Program**. This AMA will focus on Dr. Collins' experiences during the Human Genome Project and how he envisions the future of precision

medicine.



Monday, April 23, 2018

Representatives from Personal Genetics Companies

"Personal genetics and you"

Fifteen years after the completion of the Human Genome Project, we're now at a time when taking a detailed look at our genome can be as easy as ordering a kit online, spitting into a tube or swabbing the inside of the cheek and sending it off through the mail to a lab. Personal genetics companies are using these at-home, genetic-testing kits to help people access and understand their genome. The market for at-home genetic testing is ever-growing and can offer different aspects about what makes you, you! This AMA will answer your questions on what you can learn from your genome at home.

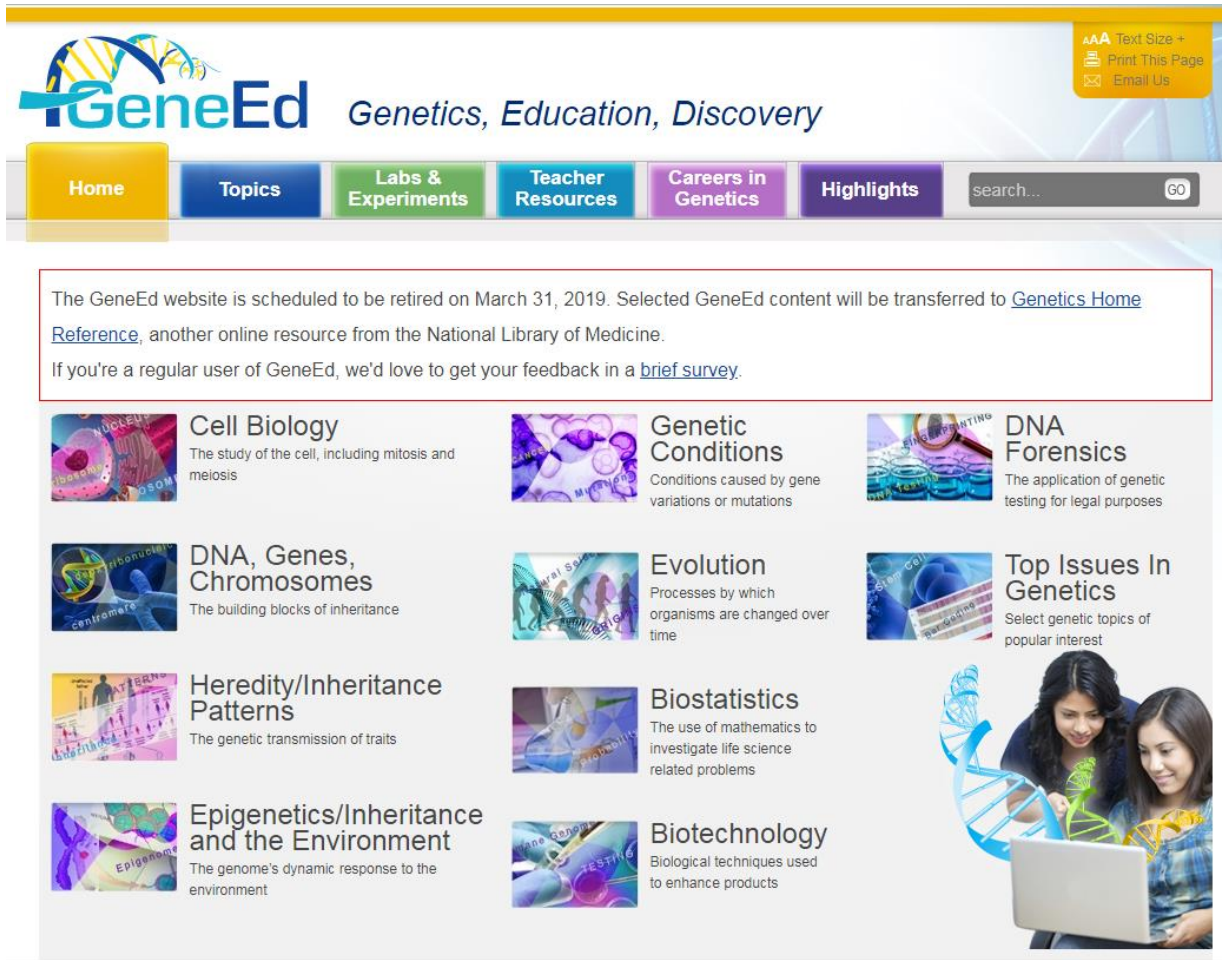


Tuesday, April 24, 2018

The Smithsonian Conservation Biology Institute's Center for Conservation Genomics researchers

Jesus Maldonado, Ph.D. and Nancy Rotzel McInerney, B.S.

K-12 Resources



The GeneEd website interface features a yellow header with the GeneEd logo and the tagline "Genetics, Education, Discovery". A navigation bar includes links for Home, Topics, Labs & Experiments, Teacher Resources, Careers in Genetics, and Highlights, along with a search bar. A notice states that the website is scheduled for retirement on March 31, 2019, with content being transferred to the Genetics Home Reference. Below the notice, a grid of eight topic cards is displayed, each with a representative image and a brief description.

Cell Biology
The study of the cell, including mitosis and meiosis

Genetic Conditions
Conditions caused by gene variations or mutations

DNA Forensics
The application of genetic testing for legal purposes

DNA, Genes, Chromosomes
The building blocks of inheritance

Evolution
Processes by which organisms are changed over time

Top Issues In Genetics
Select genetic topics of popular interest

Heredity/Inheritance Patterns
The genetic transmission of traits

Biostatistics
The use of mathematics to investigate life science related problems

Epigenetics/Inheritance and the Environment
The genome's dynamic response to the environment

Biotechnology
Biological techniques used to enhance products

[GeneEd](#)



The Harry Potter's World website interface features a dark blue header with the NIH logo and the title "HARRY POTTER'S WORLD: RENAISSANCE SCIENCE, MAGIC, AND MEDICINE". A navigation bar includes links for Databases, Find, Read, Learn, Explore NLM, Research at NLM, and NLM for You. The main content area includes a large owl illustration and a text box about the Harry Potter series. Below this, there are three sections: "LEARN more", "SEE the digital gallery", and "BOOK the traveling exhibition", each with a representative image and a "FIND OUT" button.

HARRY POTTER'S WORLD
RENAISSANCE SCIENCE, MAGIC, AND MEDICINE

In 1997, British author J. K. Rowling introduced the world to Harry Potter and a literary phenomenon was born. Although a fantasy story, the *Harry Potter* book series features magic that is based partially on Renaissance...

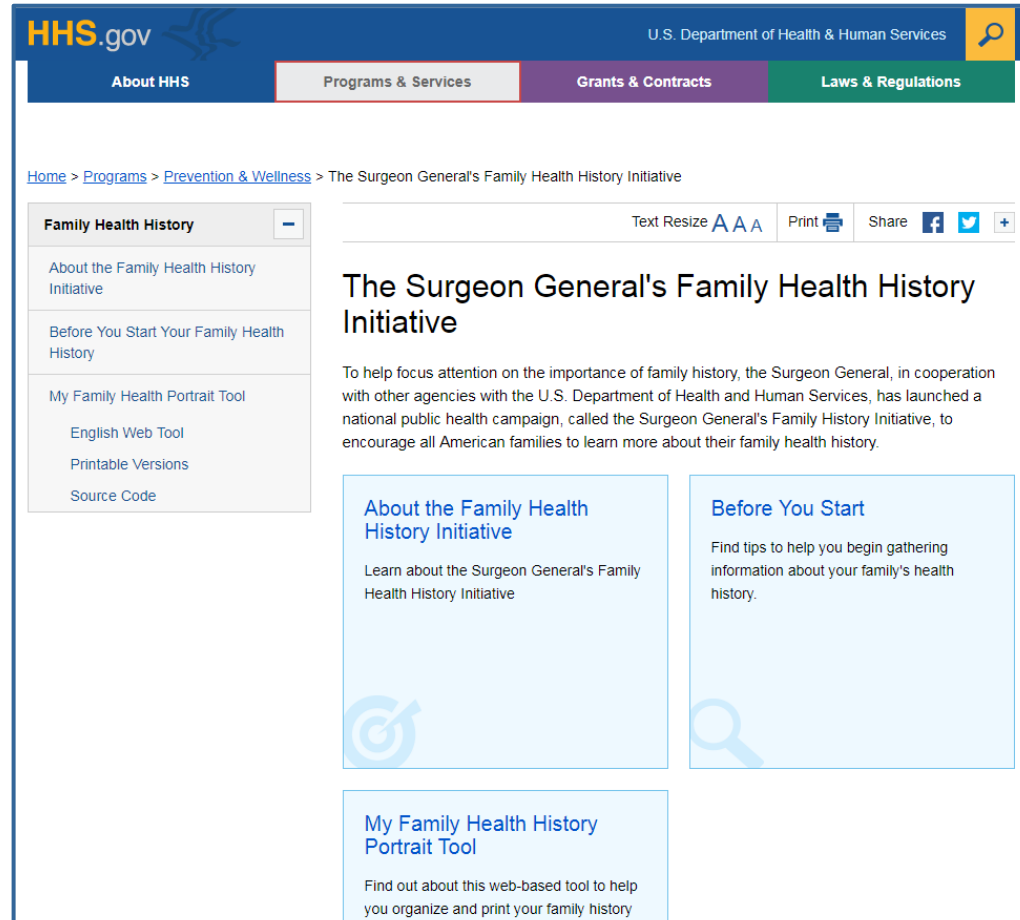
LEARN more

SEE the digital gallery

BOOK the traveling exhibition

[Harry Potter's World](#)

My Family Health Portrait U.S. Surgeon General

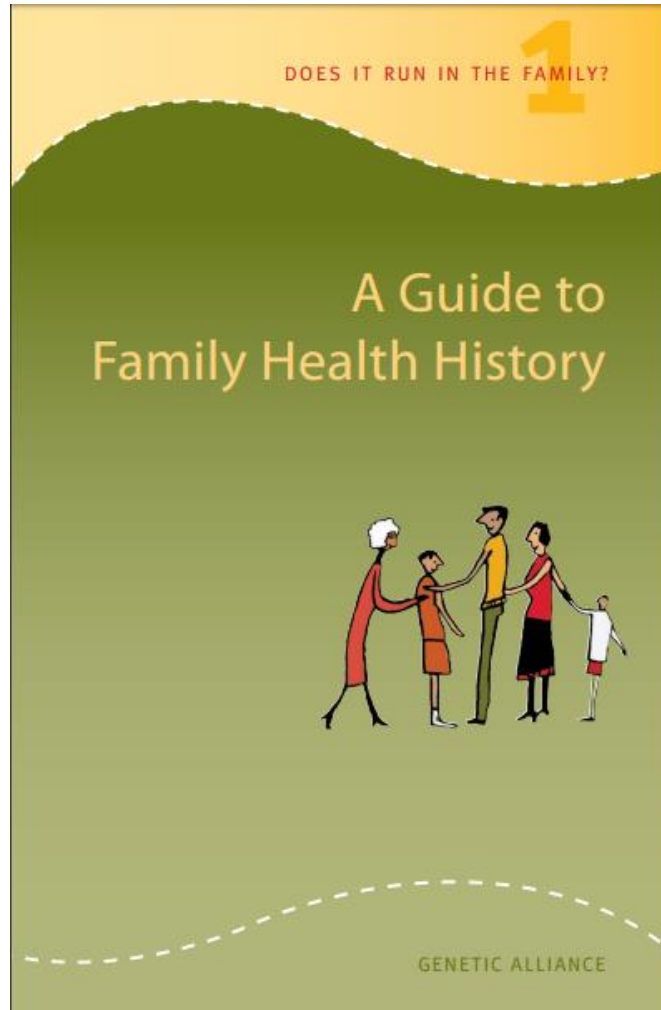


The screenshot shows the HHS.gov website with the following structure:

- Header:** HHS.gov logo, U.S. Department of Health & Human Services, and a search icon.
- Navigation Bar:** About HHS, Programs & Services (highlighted), Grants & Contracts, and Laws & Regulations.
- Breadcrumbs:** Home > Programs > Prevention & Wellness > The Surgeon General's Family Health History Initiative
- Left Sidebar:**
 - Family Health History** (dropdown menu)
 - About the Family Health History Initiative
 - Before You Start Your Family Health History
 - My Family Health Portrait Tool
 - English Web Tool
 - Printable Versions
 - Source Code
- Main Content Area:**
 - Title:** The Surgeon General's Family Health History Initiative
 - Text:** To help focus attention on the importance of family history, the Surgeon General, in cooperation with other agencies with the U.S. Department of Health and Human Services, has launched a national public health campaign, called the Surgeon General's Family History Initiative, to encourage all American families to learn more about their family health history.
 - Three Content Boxes:**
 - About the Family Health History Initiative:** Learn about the Surgeon General's Family Health History Initiative.
 - Before You Start:** Find tips to help you begin gathering information about your family's health history.
 - My Family Health History Portrait Tool:** Find out about this web-based tool to help you organize and print your family history.
- Utility Bar:** Text Resize (A A A), Print, Share (Facebook, Twitter, etc.), and a plus icon for more options.

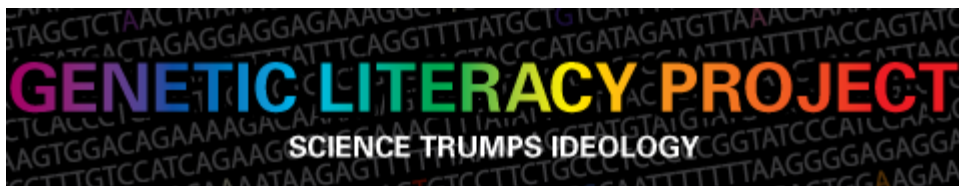
[Surgeon General's Family Health History Initiative](#)

Does It Run In the Family? Toolkit



[Does it Run In the Family? toolkit](#)

Literacy/Education Resources



Ethics and Privacy

Societal Concerns

- Who should have access to personal genetic information, and how will it be used?
- Who owns and controls genetic information?
- How does personal genetic information affect an individual and society's perceptions of that individual?
- How will genetic tests be evaluated and regulated for accuracy, reliability and utility?
- Where is the line between medical treatment and enhancement?
- Should testing be performed when no treatment is available?

GINA

GINA

GENETIC INFORMATION
NONDISCRIMINATION ACT

About | Contact

Genetic Information

What is genetic information and why is it important?

GINA & Health Insurance

What are GINA's health insurance protections?

GINA & Employment

What are GINA's employment protections?

What is GINA?

The Genetic Information Nondiscrimination Act of 2008 (GINA) is a federal law that protects individuals from genetic discrimination in health insurance and employment. Genetic discrimination is the misuse of genetic information. This resource provides an introduction to GINA and its protections in health insurance and employment. It includes answers to common questions and examples to help you learn. Choose from one of the boxes to the left to begin!

✉ Have questions, comments or suggestions? [Send us a note.](#)

🖨 [Click here](#) for a printer friendly version.

✉ For healthcare provider resources [click here.](#)

🖨 [Click here](#) for the GINA & You Information Sheet

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[GINA Help](#)

H. R. 1313

CONGRESS.GOV

Legislation Congressional Record Committees Members Sign In

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All Legislation Examples: hr5, sres9, "health care"

Home > Legislation > 115th Congress > H.R.1313

H.R.1313 - Preserving Employee Wellness Programs Act
115th Congress (2017-2018) | [Get alerts](#)

BILL Hide Overview

Sponsor: [Rep. Foxx, Virginia \[R-NC-5\]](#) (Introduced 03/02/2017)

Committees: House - Education and the Workforce; Energy and Commerce; Ways and Means

Committee Reports: [H. Rept. 115-459](#)

Latest Action: House - 12/11/2017 Placed on the Union Calendar, Calendar No. 341. ([All Actions](#))

Tracker:

Introduced Passed House Passed Senate To President Became Law

More on This Bill
[Constitutional Authority Statement](#)
[CBO Cost Estimates \[1\]](#)

Subject — Policy Area:
Health
[View subjects >](#)

Summary (1) Text (2) Actions (13) Titles (3) Amendments (0) Cosponsors (5) Committees (3) Related Bills (0)

Summary: H.R.1313 — 115th Congress (2017-2018) [All Information](#) (Except Text)

[Listen to this page](#)

There is one summary for H.R.1313. [Bill summaries](#) are authored by [CRS](#).

Shown Here:
Introduced in House (03/02/2017)

Preserving Employee Wellness Programs Act

This bill exempts workplace wellness programs from: (1) limitations under the Americans with Disabilities Act of 1990 on medical examinations and inquiries of employees, (2) the prohibition on collecting genetic information in connection with issuing health insurance, and (3) limitations under the Genetic Information Nondiscrimination Act of 2008 on collecting the genetic information of employees or family members of employees. This exemption applies to workplace wellness programs that comply with limits on rewards for employees participating in the program.

Workplace wellness programs may provide for more favorable treatment of individuals with adverse health factors, such as a disability.

Collection of information about a disease or disorder of a family member as part of a workplace wellness program is not an unlawful acquisition of genetic information about another family member.



The NEW ENGLAND JOURNAL of MEDICINE

Perspective
JULY 6, 2017

Undermining Genetic Privacy? Employee Wellness Programs and the Law

Kathy L. Hudson, Ph.D., and Karen Pollitz, M.P.P.

Genetic information is becoming ubiquitous in research and medicine. The cost of genetic analysis continues to fall, and its medical and personal value continues to grow.

The Genetic Information Nondiscrimination Act of 2008 (GINA) prohibits both employment and health insurance discrimination based on genetic information, and

PMID: 28537794

Usage by law enforcement


AMERICA

In Hunt For Golden State Killer, Investigators Uploaded His DNA To Genealogy Site

by LAUREL WAMSLEY

April 27, 2018 • After failing to find a match within criminal databases, law enforcement uploaded the killer's DNA profile to a no-frills website used to trace ancestry. The tactic has spurred privacy concerns.

NIH National Human Genome Research Institute


National Human Genome Research Institute


Search Genome.gov

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Issues in Genetics


Policy, legal and ethical issues in genetic research




Coverage and Reimbursement of Genetic Tests
Information about insurance coverage for genetic testing




Human Subjects Research
Human subject participation for biomedical, clinical and social-behavioral research




Genetic Discrimination
How Americans are protected from discrimination based on their genetics




Regulation of Genetic Tests
How the federal government regulates genetic tests.




Privacy in Genomics
How best to ensure that genomic information remains private




Informed Consent
The rights of participants when consenting to research projects



Intellectual Property and Genomics
Can a gene be patented?




Genomics and Health Disparities
Ensuring that all populations benefit from the advances of genomics research



Genome Statute and Legislation Database
A database of state statutes and bills from 2007-2017 U.S. state legislative sessions


Highlights

Improving science policy and healthcare through the NHGRI-ASHG fellowship



The health and medical care of Americans is greatly influenced by the policy decisions that guide genomic research. NHGRI and the American Society for Human Genetics (ASHG) are committed to strengthening the workforce of policy makers and analysts with genetics professionals through their Genetics and Public Policy Fellowship. The 2017-2018 fellow, Nikki Meadows, Ph.D., has just finished her first rotation at NHGRI. Learn about her experiences and what motivates her to pursue a career in science policy.

New policy to protect research participants of NIH-funded research



The 21st Century Cures Act, enacted December 13, 2016, strengthened privacy protections for research participants. Now, a new policy specifically requires additional protections for sensitive information collected from participants as part of federally-funded research. The National Institutes of Health (NIH) recently put forth this new policy requiring all NIH-funded

See Also

- Policy and Program Analysis Branch
Staff Contact Information
- [Ethical, Legal and Social Implications Research Program](#)
NHGRI's Extramural Research Program
- GenomeTV
NHGRI's YouTube Channel
- Issues in Genetics Archive
Past Web content from the Issues in Genetics Portal
- Social and Behavioral Research Branch
NHGRI Intramural Research Program
- Online Bioethics Resources
Links to bioethics resources from around the Web

Informing the Public



CENTER FOR
GENETICS AND
SOCIETY



All of Us

1 MILLION + VOLUNTEERS

Precision Medicine



Precision medicine is an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person.

Instead of what treatment is right for this disease it is what treatment is right for the patient.

[Precision Medicine Initiative announcement](#)


All of Us Research Program

The mission of the *All of Us* Research Program is to accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care for all of us.

NIH National Institutes of Health
All of Us Research Program

ABOUT ▾ FUNDING ▾ NEWS, EVENTS, & MEDIA

[JoinAllOfUs.org](#) Search



The future of health begins with *All of Us*

The *All of Us* Research Program is a historic effort to gather data from one million or more people living in the United States to accelerate research and improve health. By taking into account individual differences in lifestyle, environment, and biology, researchers will uncover paths toward delivering precision medicine.

[WATCH VIDEO](#)

We're beta testing. Director Eric Dishman introduces the program.

[WATCH VIDEO](#)

Sign up to be notified of announcements, events, funding news and more.

[SUBSCRIBE](#)

[All of Us Research Program](#)

All of Us Research Program- video



[What is All of Us? video](#)

All of Us – more information



The future of health begins with **All of Us**

The *All of Us* Research Program is a historic effort to gather data from one million or more people living in the United States to accelerate research and improve health. By taking into account individual differences in lifestyle, environment, and biology, researchers will uncover paths toward delivering precision medicine.

WATCH VIDEO ▶



We're beta testing. Director Eric Dishman introduces the program.

WATCH VIDEO ▶

Sign up to be notified of announcements, events, funding news and more.

SUBSCRIBE

[All of Us Research Program](#)

Library role

“Preparing the public to make educated personal and family health decisions in a time of rapidly evolving genetic and genomic knowledge will require new partnerships between the education system, health care systems, the government, community advocacy organizations, consumers and the media.”

Show What You Know!

1. The CDC's top 10 causes of death all have a genetic component.
True or False?
2. The American College of Medical Genetics and Genomics (ACMG) recommends everyone should use a direct to consumer genetic test.
True or False?
3. What is the name of the research program that is looking to collect data on 1 million volunteers in order to provide more precise health care through prevention and treatment?
4. GINA (Genetic Information Nondiscrimination Act) protects you from life insurance discrimination.
True or False?
5. What resource would you recommend to patrons who wanted to learn more about genetic testing?

Thank You!

Carolyn Martin, MLS, AHIP
NNLM PNR
martinc4@uw.edu

